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ABSTRACT

Issues in working with mentally retarded parents are considered. Experiences of the Intensive Services to Families at Risk Project (ISFAR), an effort to prevent the need for foster care by improving the quality of care for abused and neglected children in their own families, are recounted. Among problems facing retarded parents are a tendency to overgeneralize instructions, difficulty in adjusting parenting styles to changes in child's development, and lack of such vital resources as transportation for medical services or clothing. ISFAR services addressed child care knowledge, parent child interaction, resource deficits, and family supports. In addition, parents were helped to interact with various human service agencies. Activity groups were used to improve parenting abilities, and individual sessions were devoted to unique needs. Benefits of the program are traced, and the need for an array of services is stressed, including skill training, home visiting, and casework designed to reduce resource and social problems. (CL)

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INTELLECTUALLY HANDICAPPED MOTHERS: PROBLEMS AND PROSPECTS

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Many mentally retarded parents, never taught the skills needed to properly nurture a child, find themselves on a one-way street in America. That street leads to the courts when the parents are accused of mistreatment or inadequate caretaking - and the courts often take the child away.

Few resources exist to help mentally retarded parents deal with the problems of parenting. In addition, this population is growing as more and more mentally retarded citizens move into community settings and assume parenting roles.

Can mentally retarded people learn to be good parents? The answer is not simple and mental retardation is not the only issue involved.

The staff of the Intensive Services to Families at Risk Project (ISFAR), a program at the University of Nebraska Medical Center, has worked with both retarded and non-retarded parents who have been referred for serious parenting problems. ISFAR was one of seven research and demonstration projects funded by the Administration for Children, Youth and Families (ACYF) for the prevention of the necessity of placing children in foster care. ISFAR was in operation for the period of funding, which began in September, 1977 and ended in March, 1981.

The objective of ISFAR was to prevent the need for foster care by improving the quality of care abused and neglected children received in their own families. This was accomplished by providing a wide range of services to

families. The services were designed to produce improvements in parents' child care practices and usually included weekly home visits, group meetings and referrals to other agencies. This paper will discuss ISFAR's findings regarding mentally retarded mothers and will present guidelines for the kinds of services they need.

About 10 percent of ISFAR's former clients are retarded and this retardation has had a significant impact on how the community evaluates their parenting skills, what services are available to them and how they learn new skills. Most of these retarded parents were not willfully abusing or neglecting their children; however, through a lack of knowledge and mistakes in judgement, they have not provided adequate care for their children. The overwhelming majority of these parents were single mothers and like most retarded persons who live in the community and have children, the parents were labeled borderline or mildly retarded.

It has become clear to us that for people in the borderline or mild range of retardation, I.Q. is not a good predictor of the ability to parent; parents with similar scores on intelligence tests can display substantial differences in commitment to their child and in their capacity to meet that commitment. One mentally retarded parent whose child was developmentally delayed was able to make significant personal sacrifices to provide the child with needed services. Another parent resisted a necessary change in her son's educational placement because she liked the socialization available to her at his present placement and worried about the effect of the change upon herself.

Concerns for one's child can provide the motivation for parents to learn

good parenting skills. For this particular population, concern and willingness to place a child's need ahead of one's own immediate wants are often more important predictors of the ability to improve child care skills than is intelligence.

Parents who are mentally retarded and referred for inadequate parenting share many characteristics with parents in the general population who have similar caretaking problems. For almost all of these parents, childhood and socioeconomic ackgrounds and present living conditions are major sources of current child care problems. In most cases, these are the same reasons and conditions that make it hard for people who are not mentally retarded to be good parents. Some conditions known to exacerbate inadequate caretaking include: poverty, unemployment, lack of vocational skills, apathy, growing up with poor parenting models, isolation from extended family and social supports, lack of experience in living resulting from overprotectiveness.

These factors are not uncomon in the lives of many mentally retarded individuals. Indeed, most of the mentally retarded parents we have served live on inadequate incomes, have limited job skills, are socially isolated, and have few social supports. This lack of support is often due to conflicts with extended family and to limited skills in making friends.

Another common problem which reduces their social supports stems from the tendency of these parents to overtax the supportive people available to them. One retarded single parent had a large extended family, whose members she took turns "visiting". They eventually became exhausted and were no longer willing to assume responsibility for her and her child.

Mentally retarded parents often lack the skills and resources needed to provide adequate care for their children and they may have somewhat greater difficulty learning new parenting skills. However, they can and do learn parenting skills if they have a commitment to change and have access to resources, social supports, and training appropriate to their needs. All parents who mistreat their children need services, and mentally retarded parents are no exception. These parents need a comprehensive range of services including home visiting, skill training, and group and social network supports.

While similarities of services and training needs for abusing and neglecting parents outweigh the differences, parents who are retarded do present some unique problems. First, the parents we worked with had a tendency to overgeneralize their instructions and we found that we had to be very specific when telling them how to carry out their parenting responsibilities. It was not enough to help a mother change one or two aspects of the way she parented and then expect her to improve other child care skills without additional assistance. One young mother did not know how to cook and did not feed her child adequately. As a result, her child was not gaining weight. To teach cooking skills the worker and the young mother made pancakes together. The mother proceeded to feed the child pancakes for breakfast, lunch, and dinner.

Another challenge we encountered was the difficulty these parents had in adjusting parenting styles to changes in their child's development. For example, one mother learned certain games to play with her infant when he was nine months old. When the mother was seen a year later, she was still attempt-

ing to engage the child in the same games although they were now inapropriate. Consequently, parent training in the home and in groups must provide instruction and follow-up that permits monitoring of the way parents execute parenting instructions and modifications of their instructions as it becomes necessary.

The primary focus of our efforts has been to enhance the quality of care the children receive. To do this we addressed problems in the areas of child care knowledge, parent-child interaction, resource deficits, and family supports.

Resource problems, including inadequate transportation for medical services or inadequate amounts of food, are common problems for these families. To cope with these difficulties, it was sometimes necessary to offer direct assistance such as providing food or a winter coat. More often we helped the family to locate resources in the community. It was also necessary to assist in the management of resources such as food and money. Teaching parents to manage money, to monitor their food supplies, and to use economical foods were common topics for discussion during weekly visits and during some group meetings.

We also assisted the families in negotiating the complexities of the various components of the human services system. We used these occasions to demonstrate to parents how to advocate for themselves. Teaching self-advocacy often involved role playing prior to going to appointments, this included meetings with child's teacher, or talking to a landlord.

Generally this role play began by talking about the purpose of the appointment, what kind of questions would the client ask, what kind of ques-

tions would be she asked. The worker would then pretend to be the landlord or welfare worker. They would practice asking questions and even choose some useful phrases to use. They might discuss how the client should dress, and the importance of maintaining eye contact. Initially the worker accompanied the client to the appointments and afterwords they would discuss what had occured. As the clients grew more confident it was not necessary to accompany them. It was common to encourage the client to ask more questions when needed or say simply "I do not understand what you mean". One young mother who initially had many difficulties with the welfare department was able, over a three month period, to start being appropriately assertive and even request an appeal when she felt her rights had been denied. Despite her success, when a conflict arose with the day care center, some steps had to be repeated, at least briefly until she felt confident. Many of our parents did gradually increase their ability to advocate for themselves without the need for reminders or corrections. As their confidence in their ability in other areas increased, it had a positive impact on their self-advocacy skills.

Activity groups for improving clients' parenting abilities proved to be very useful. The focus of these groups was on skill learning, problem solving, and support. All of our retarded mothers were involved in at least one group.

The first group was a mother-child swim group that met weekly for six weeks. This group was small and highly supervised. It focused on improving the quality of interaction between parent and child. The group aquatic activities constituted the vehicle through which mothers and children engaged

in mutually enjoyable activities. The staff encouraged the parents to think of what they were doing as teaching their children to enjoy the water. This was a new and positive image of themselves. On one occasion a parent proudly told the day care teacher about "teaching" her son to like water and indicated that she had learned how to talk to him and where to hold him so that he felt safe. This was one of the first times she had felt competent as a parent. The staff also used the swimming group as an opportunity to teach parents how to dry and dress their wet squirming children. As in other groups the parents learned from each other. A parent who successfully used games such as "find the hand", to enlist her child's cooperation in dressing encouraged two other parents to use this strategy.

A second group, which met regularly for more than a year, was devoted to discussions and demonstrations of appropriate child care procedures. Topics covered in this group included child discipline, safety in the home, and toilet training. Instructions were given to parents in a more concrete manner than ordinarily used in parent education groups. In most parent groups information is given in general statements, such as, "children of 10 months put things in their mouths." Parents who are retarded may understand the words but not be able to translate them to mean "do not leave small items on the floor." Thus, during a session on "child-proofing" a room, the group first talked about what needs to be done. The parents then went into a mock living room and practiced child-proofing it for children who could crawl, who could walk, and who were able to climb. Whenever possible the group leaders modeled ways of observing changes in a child's development and modifying parenting to fit those changes.

A substantial portion of this group's time was spent addressing the problems raised by parents. This included their frustration at being treated as inadequate parents but not knowing what they were doing wrong. The group also advised one another, as when they told one mother that punishing her small child by standing him in the corner for hours, a strategy that she had learned when she was in an institution, was improper and suggested less harsh disciplinary procedures.

A third group, a mother-child play group, was also established. During these meetings, staff introduced parents to new toys. Mothers learned about toys and used them in play with their children. These groups provided opportunities for the kind of playful interactions between parents and children that rarely occured elsewhere for these families. Parents were able to see the leaders modeling appropriate play behavior and, at the same time, had some of their needs for play fulfilled. The group offered an excellent forum for demonstrating concrete ways of handling discipline problems.

On one occasion a mother had considerable difficulty toileting her three year old and his cries were heard quite clearly by group members. When the mother and son returned, the group leader asked "what had happened?" After the mother related her frustration over toileting her son one worker took charge of the children while the other leader and mothers moved to another part of the room to work on the problem. Some alternative strategies for toileting were suggested. The group leader and the mother tried them out at home later that week. The following week this mother was applauded by the group when the toileting trip was accomplished with much less conflict.

Intergration of information from the group and the monitoring of its

application in the home occurred during home visits. Instruction during home visits was designed to insure generalization and to provide additional opportunities for modeling, practicing, and clarifying new information.

The capacity and the needs of our families varied, and in some instances it was appropriate to involve extended family or members of the families' social network in the sessions directed to improving child care skills. This was usually done through home visits, although members of the extended family were occasionally invited to group meetings. Contact with families and clients in the client's network was important in strengthening the network and making needed support available. Sometimes this contact involved resolving conflicts or working out living arrangements. On occasion this resulted in the extended family assuming responsibility for the child when it became clear that the client did not have this capacity. The client's network also included the professionals working with the family. Consequently, it was often important for us to coordinate the activities of several service agencies.

Group participation also had the effect of increasing social support. We discovered early that even if the group focused on learning about child care, part of each session should be directed toward meeting the social needs of the parents. In fact this need was so great that part of each home visit also had to be devoted to the parent's needs.

Friendships formed among some of the parents and led to phone contact between group meetings. This socialization was important for promoting selfworth and for providing an emotional outlet and relief from isolation

and loneliness.

In individual sessions with clients, living skills such as cleanliness, greeting people, and appropriate street behavior were discussed. At the request of several mothers, four group sessions were devoted to grooming. All of these interventions were directed at increasing the client's ability to interact successfully with adults in their environment.

Over long periods we saw important changes in some of our clients. In one instance a teenage mother, who had not been feeding her infant regularly and who had alienated clinic staff with her failure to comply with their demands for improvement, was made the focus of an intense intervention effort. Gradually she was able to learn how to feed her baby and how to cook. She developed skills in talking to clinic staff and obtaining answers to her questions. This young woman entered a job training program, made improvements in her grooming, and made friends. Her increased self-esteem was reflected in her comment that "my brother and sister say my meatloaf is better than my mother's."

At another point we worked with a couple who did not seek medical care for themselves and their children because of their fear of physicians and hospitals. Their worker was able to allay their fears by using their trust in her. This trust had developed as result of her consistency in visiting them and in assisting them in solving resource problems. The parents eventually were willing to allow their son to have needed surgery . They were able to engage with a local physician and began receiving medical care

for their own chronic health problems. With these changes accomplished they were able to improve their housing, and their income. Moreover for the first time they now had enough confidence to talk with the school about a problem one of their children was having.

Not all families made lasting improvements. After two years of intensive involvement one young mother still did not appreciate that her 2½ year old son could not protect himself from many types of accidents and that she needed to actively safeguard his welfare. At times she left him unsupervised in such potentially perilous situations as the bathtub, while she visited with friends outside their apartment. We eventually arranged a supervised placement for both mother and son; however, this plan was rejected by the mother. Shortly after this they moved to an adjoining state. The situation did not improve and the child was removed from her custody. There appears little likelihood tha he will be returned to her care.

At this point, some six months after our program terminated, many families are doing well, with no continued services. Some call occasionally but only to tell us "news" or ask advice. They don't need much assistance. Others, require continued support on a limited basis. They get this support through the visiting nurses, or the local agency serving retarded adults. A few parents as in the last example do not make enough changes to adequately care for their children and substitute families must be found for the children.

We have found that retarded parents can have serious difficulties in caring for their children. However, to a large extent the child care pro-

blems of parents whose intellectual abilities fall into the borderline or mild range of retardation stem more from problems in their own upbringing and their living situations than from intellectual deficits.

It is clear that many of these parents can be helped to be better parents. What is needed is a mix of services that begins with casework geared toward reducing their resource and social problems. They also require skill training presented in a manner that they can understand. Finally, they need home visiting that is designed to monitor household functioning and to follow up skill training activities.

Services directed to the special learning needs of retarded parents are needed now and will continue to be needed in the future. Future programs should include the components we provided and in addition should offer opportunities for parents to have supervised practice in playing with their children in a pre-school setting. Although many of our children did attend child care centers, it was rare that we were able to arrange for the parents to receive supervised practice.

Our society has made a commitment to the rights of the mentally retarded and to maintaining the integrity of families. Such a commitment implies that we must have the services that are needed to make this goal a reality.